
Innovative Service Delivery Strategies for Fetal Alcohol Spectrum Disorders: Recreational and Educational Summer Programs

A Report from the
Substance Abuse and Mental Health Services Administration
Fetal Alcohol Spectrum Disorders
Center for Excellence

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Part 1: Overview of Summer Programs for FASD

INTRODUCTION

Each year, as many as 40,000 babies in the United States are born with fetal alcohol spectrum disorders (FASD), costing the Nation about \$4 billion. FASD is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications. The term FASD is not intended for use as a clinical diagnosis. It refers to conditions such as fetal alcohol syndrome (FAS), alcohol-related neurodevelopmental disorder (ARND), and alcohol-related birth defects.

To help address FASD, the Substance Abuse and Mental Health Services Administration (SAMHSA) launched the FASD Center for Excellence in 2001. The Center's goals are to advance the field of FASD and facilitate the development of comprehensive systems of care. Among the Center's six legislative mandates is a requirement to study innovative clinical interventions and service delivery improvement strategies.

The Center's mandate to study interventions and service delivery stems from the lack of tested strategies for addressing FASD. SAMHSA defines "best practices" as "practices that incorporate the best objective evidence currently available regarding effectiveness and acceptability." For most complex problems observed in individuals with an FASD, the search for best practices remains elusive. To date, no controlled studies have demonstrated the effectiveness of any intervention on any of the problems seen in persons with an FASD.

In the absence of tested methods, parents and caregivers of persons with an FASD have attempted to develop effective interventions. From these family efforts, the family camp concept in FASD intervention emerged. For many reasons, summer camps are considered a possible promising practice for intervening with children, youth, and families affected by FASD.

To explore summer family programs as an intervention strategy, the FASD Center supported two pilot programs: one in Michigan in August 2002 and one in Washington in August 2003. The programs provided educational and recreational activities for children, adolescents, and young adults with an FASD. The programs also included training and respite for parents and caregivers.

This report describes the origins of summer programs for persons with special needs, special needs camps as a promising practice, and details of the Michigan and Washington programs. It also discusses whether family camps for persons and families affected by FASD can be considered a promising practice. Finally, the report includes an agenda, which may help individuals and organizations interested in planning similar programs.

ORIGINS OF SUMMER PROGRAMS FOR PERSONS WITH SPECIAL NEEDS

From its inception, summer camping has been touted as a valuable learning experience and rite of passage for American youth. The first organized summer camp was initiated in the United States in 1861 at a military school for boys. Private camps started in the 1880s and YMCA, Boy Scout, and Camp Fire Girls camps in the 1890s. By 1914, summer camping was described as "an experience that every boy and

girl should have....Camping intensifies friendship and friendship furnishes the motive and reward of most of our efforts.”¹

Since the early 20th century, camping has thus been perceived as a key component in the social development of children and youth. For families of individuals with an FASD, the summer camp could be viewed as the answer to their children’s isolation and loneliness. It could also provide much-needed respite and a chance to bond with similar families.

Mitchell and Meier defined organized camping as “a community of persons living together as an organized, democratic group in an outdoor setting.”² Trained staff supervise recreational activities based on participants’ needs and interests. The camp program focused mainly on the natural environment as a way to promote the mental, physical, social, and spiritual growth of the camper.

Today there are more than 12,000 camps in the United States with 7 million child and adolescent participants each year.³ A wide range of camps is available, including camps for youth from preschool to high school, adults, families, and individuals with special needs. The first summer day camp for children and adults with mental retardation was organized in 1963. Later, the Special Olympics was established as a summer sports program for “exceptional children.”

Although the number of summer camps has grown over the past several decades, few camps adequately serve children with special needs. The camps that do exist often have long waiting lists. Special needs camps are usually cost- and labor-intensive due to many factors, such as special diets, medication management, physical disabilities, and behavioral disorders.

Many children and adolescents with an FASD require a camping experience that addresses multiple areas of need. Due to the lack of special needs camps, especially those serving campers with the difficulties associated with FASD, families and caregivers began to develop camps for these individuals. The FASD therapeutic summer camp also borrowed from the family camp concept, which has become popular in recent years. Family camps offer activities for children, adolescents, and parents and caregivers, which can be economical and enjoyable for all involved.

For families of children and adolescents with an FASD, turmoil and stress may be part of everyday life. The concept of a summer camp specifically for FASD may give parents and caregivers respite, adult interaction, and a chance to see their children happy, successful, and relating to their peers.

SPECIAL NEEDS CAMPS AS AN EFFECTIVE PRACTICE

Research on summer camps has noted positive outcomes for children and adolescents in the United States and abroad with special needs, including:

- Various diseases such as kidney disease,⁴⁻¹⁰ diabetes,¹¹⁻¹⁴ cystic fibrosis,¹⁵ and HIV/AIDS¹⁶
- Burn injuries¹⁷
- Motor problems¹⁸ and sensory integration deficits¹⁹
- Mental retardation²⁰
- Behavior problems²¹

These special needs camps involved 5 days to 2 weeks of residential status, traditional camping activities (therapeutic sports, horseback riding, campouts, cooperative and competitive social play, etc.),

training in knowledge and management of the disability, nutritional planning, instruction in activities of daily living and independence skills, and psychosocial services for parents and youth. Children and adolescents attending special needs camps have exhibited a variety of improvements:

- Increased life adaptation and self-confidence^{12,22}
- Increased independence and self-care capacity^{7,11}
- Improvements in disease self-management¹³
- Improvement in nutritional habits and associated weight changes¹³
- Increased awareness that participants were not the only ones dealing with disability issues¹⁴
- Acquisition of more realistic “self-views”¹⁵
- Acquisition of new physical and recreational skills¹⁵
- Experience of success in cooperative and competitive situations¹⁵
- Experience of friendships¹⁵
- Decreased anxiety²³
- Positive changes in children’s behavior¹⁹

For parents and caregivers, improvements reported after the camping experience included greater awareness of their children’s skills in managing their disease¹⁴ and a welcome respite that decreased “burnout.”²²

Some success has been seen in FASD-specific programs. Evaluation data from a July 2004 FASD Training Retreat for families in Alaska indicate that the training provided to parents and caregivers was useful and provided new information. Participants indicated that they would recommend the training to others. Participants also noted that they appreciated the opportunity to meet other parents, build support networks, and see the children interact. Volunteers of America, Alaska, runs an annual “FAScinating Families” camp, but no evaluation data are available on long-term outcomes.

Despite the lack of outcome data, summer programs for individuals with an FASD and their parents and caregivers is a potentially beneficial practice. The Michigan and Washington experiences provide insight into the needs of individuals and families affected by FASD and how such needs might be addressed. The results for participating youth and adults provide some indication of whether the FASD summer program is a promising practice for this population.

MICHIGAN AND WASHINGTON FASD SUMMER PROGRAMS

The goals of the Michigan and Washington FASD programs were to:

- Provide individuals with an FASD and their caregivers with an enjoyable and educational experience.
- Facilitate networking among individuals with an FASD and their caregivers.
- Teach self-advocacy skills to individuals and families affected by FASD.

Program Concept

Although the goals were similar, the underlying concept for each program differed. For the Michigan program, a well-known nurse and FASD advocate and her adopted adult son with FAS envisioned a summer conference in a camp environment. The conference would help adolescents and adults with an FASD understand their disability and find better ways to live with it. The conference planning committee

would include individuals with an FASD, who would help plan content and activities. The conference would include lectures and small group workshops, skits, and recreational activities. In addition, a town hall meeting would be convened for participants and family members to tell experts and representatives from State and national agencies about living with an FASD.

The conference was held in a camp environment to best meet the needs of attendees with short attention spans, impulsivity, memory problems, and a need for physical activity throughout the day. Most hotel settings could not meet these needs. In addition, as people with an FASD got older, they attended conferences that did not address their needs. They wanted their own conference that would be on their level and address their needs as they see them.

The main concept was that this be a conference by and for individuals with an FASD and truly be their conference, not something developed by professionals or parents. They needed ownership, so over half of the planning committee were individuals with an FASD. The remaining committee members were support persons. Although most of the support persons were parents who had a positive experience, no part of the program was specifically planned to meet their needs.

The Washington program was more like a family camp. It was conceived by researchers at the University of Washington FAS Diagnostic and Prevention Network (DPN) and Stone Soup Group. Stone Soup helps conduct the FAScinating Families camp and provides behavior management training and self-advocacy skills to families in Alaska affected by FASD. The Washington camp focused more on educating parents and caregivers. Objectives included:

- Give parents of children with an FASD an opportunity for respite, education, and networking. Training topics included Positive Behavioral Support (PBS), advocacy, and sensory integration.
- Give children with an FASD the opportunity to interact with other children in supported and well-supervised recreational and social activities.
- Provide opportunities for siblings to meet and interact with other siblings of children with an FASD.

Program Content

The Michigan conference was designed primarily by and for adults with an FASD. Its main objective was to provide professionally conducted education. Various professionals gave lectures on topics such as:

- Understanding the disabilities associated with FASD
- Coping with disabilities
- Self-advocacy
- Employment issues
- FASD prevention
- Anger management
- Dealing with the criminal justice system
- Social skills building through practice

Participants also engaged in age-appropriate social and recreational activities. The content was based on the “wisdom of practice” of families, professionals, and caregivers who were caring for individuals

with an FASD or researching the disorders. Content was based more on what had been learned from experience than on any particular theory.

The Washington camp content included a theory-based intervention, PBS, as well as advocacy skills and ways to restructure the environment for children with sensory issues. The camp also included family networking opportunities, caregiver respite and stress reduction, family-strengthening activities, and age-appropriate therapeutic social and recreational activities. The camp was originally designed for children in middle childhood but actually included infants through late adolescents.

Both sites were specifically designed for a special needs population. Activities in Michigan included swimming, boating, horseback riding, wall climbing, line dancing, drumming, and campfires. Washington camp activities included swimming, crafts, ball play, trampoline, miniature golf, baking, and science projects. In addition, the Washington camp offered clowns, magicians, carnivals, and slumber parties for youth. Caregiver respite opportunities included massage, scrapbooking, and blanket making. Both sites provided structure, stimulation, relaxation, and social interaction for the families.

Participants and Staff

The Michigan conference had 77 attendees (32 parents and caregivers, 8 professionals, and 37 participants with an FASD). Four of the caregivers were birth mothers, and the rest were foster or adoptive parents or other caregivers. Each participant was required to have a support person throughout the conference. Participants ranged in age from 15 to 37 years, with at least half having a criminal justice history. Participants appeared to range from mildly to severely disabled.

The Washington camp had 49 attendees, including 16 parents and caregivers and 33 children and adolescents. There were two birth families and seven foster and adoptive families. Camp participants ranged in age from 11 months to 19 years. Twenty-two children were diagnosed with some sort of an FASD and 11 were biologic, foster, and adoptive siblings or friends. Individuals with an FASD ranged from mildly to profoundly disabled, with most functioning in the mild range.

Although it had not been originally planned, several caregivers could not attend the Washington camp without bringing the entire family. This change helped create an integrated camp, with typical youth interacting with youth with an FASD. During the day, campers were divided into age-appropriate groups (with an approximate 1:3 counselor-camper ratio), as in typical summer camps. Counselors had received intensive prior training in special needs and the needs and issues of persons with an FASD.

Partners and Sponsors

The Michigan conference was partially supported by the SAMHSA FASD Center with contributors, supporters, and sponsors from over 16 additional private and public agencies. Speakers were from major government and research organizations involved with FASD.

The Washington camp received major support from the SAMHSA FASD Center. The Stone Soup Group provided the PBS and advocacy training for parents. DPN provided participants and staff, and the Volunteers of America provided the campground and counselors.

Outcome and Process Evaluations

The most striking outcome of both programs was the lack of major disruptive behavior by any of the participants, despite prior criminal justice system involvement or a history of challenging behaviors.

Thus, both programs provided a supportive environment and staff to minimize difficulty. Structure, small groups, and frequent breaks contributed to positive outcomes.

Both programs used a process evaluation to determine:

- Fidelity of the program to planned procedures
- Knowledge gained
- Participant satisfaction

Michigan

The Michigan conference included an onsite evaluation and a 3-month followup. Questions for individuals with an FASD addressed knowledge of FASD prevention techniques, neurologic dysfunction associated with FASD, self-advocacy skills, dealing with police matters, and anger management. Individuals were also asked about their favorite activities (“name two cool things you did at this conference”).

Caregivers were asked what should stay the same and what should be changed if the conference were replicated. They were also asked what procedures could be used to help individuals with an FASD remember what they had learned and which parts of the conference were most helpful. Followup questions asked about:

- Procedures used to reteach information taught at the conference
- Participation of persons with an FASD in FASD-related prevention activities or presentations
- Changes made in the life of the person with an FASD
- Topics that should be addressed at future conferences
- Problems encountered related to the conference

Between one-half and three-fourths of caregivers answered onsite questionnaire items and 20 to 27 percent answered followup items. One-fourth to one-half of individuals with an FASD completed onsite evaluation items. Poor fine motor control, difficulty thinking and writing at the same time, and problems putting ideas on paper made evaluation a huge challenge. However, participation in the evaluation process was better than expected.

The knowledge questions for participants indicated that most could associate drinking alcohol during pregnancy with FASD. Regarding self-advocacy, one-third indicated that personal responsibility was most important. The remainder selected community education, seeking assistance, and FAS awareness as ways to achieve this goal. When asked about how to respond when stopped by the police, most individuals replied that they should provide standard information and control their emotions. Few reported that they should mention their FASD, although this response was suggested at the conference.

When asked what to do when they felt anger, most of the persons with an FASD who responded stated that they should redirect their energy and maintain self-control. Few reported that they should communicate their feelings. When asked which activities they preferred, half reported that they enjoyed the outdoor activities the most and the other half reported that they enjoyed indoor activities and friendships.

Caregivers said that the most valuable aspects of the conference were the structure, teaching sessions, and professionals in attendance. Major areas for change included scheduling/length (“too short”) and activities. Most caregivers who responded cited review sessions/reminders, communication, and support groups as most helpful in reinforcing knowledge for persons with an FASD. Caregivers found the adult interaction the most helpful part of the conference, with interaction among individuals with an FASD, interaction with experts, and the opportunity to be heard also of significance.

At followup, most caregivers responded that they had or would use community education and FASD training to reteach the knowledge acquired at the conference. Only a small number stated that they would use reminders. Over half the responding caregivers stated that the individual with an FASD had attended FASD prevention activities or presentations, but the percentage who had regularly attended these events before the conference was not known.

Most caregivers reported that the conference helped them feel that they were not alone and increased their self-confidence and self-advocacy skills. Coping strategies were suggested as the most important topic that should be discussed in future conferences. In addition, most caregivers responded that more planned activities for individuals with an FASD should be offered in future conferences. They also thought that making new friends and relating to other individuals with an FASD was a major contribution of the conference.

It is difficult to determine whether new knowledge was acquired by individuals with an FASD, because no baseline questions were asked and most participants did not respond to the questionnaires. However, verbatim responses of participants indicated that they had enjoyed the conference and had probably learned new social and recreational skills. The caregivers clearly benefited from the networking, socialization, and information. Some wanted a longer program.

The high level of structure and organized activities for individuals with an FASD and their caregivers were major factors in the conference’s success. However, carryover from the conference could not be determined by the followup questions and responses. Rehearsal of material learned at the conference was not common and most likely persons who were active in FASD-related activities before the event remained active after.

Washington

The Washington camp evaluation achieved a 100 percent participant response rate onsite and a 73 percent 3-month followup response rate. Most of the parents and caregivers thought that the camp was worthwhile and met their children’s needs. They were satisfied with the camp length, structure, supervision, and safety and thought that the camp was well organized and should be recommended to others. Parent networking, relaxation activities, and the children’s interaction with peers were viewed as extremely important components of the camp. The camp counselors were also asked about their satisfaction with the camp. Most echoed the parents about the importance of the camp’s organization, structure, and supervision.

Most of the parents and caregivers were satisfied with the parent training workshops. All three trainings (PBS, sensory integration, and advocacy) got high marks. Most parents and caregivers wanted to attend similar camps in the future.

Followup results indicated that parents retained the basic tenets of the PBS process over the 3-month period. They found PBS to be helpful and said that they had applied information learned. Most had also

shared information about PBS with others. Although all caregivers attending reported that their children displayed challenging behavior, most had never been instructed in PBS.

The 4 days of parent training, networking, respite, and structured, age-appropriate, therapeutic social and recreational activities for children were important to participating campers. No questions were asked about improvements in the children's behavior or overall functioning after the camp or the caregivers' sense of well-being. Thus, long-term effects on behavior and functioning are not known. However, 1-year followup information collected at a 2004 camp indicated that participants remained in contact with individuals they met in 2003 and had more confidence, access to resources, advocacy skills, and knowledge about individualized education plans. Most of the parents and caregivers attributed these improvements to the camp experience.

Evaluation results from the 2004 camp in Washington indicate that the camp was successful. Results of a 3-month followup indicate that participants have kept in touch with families they met at the camp, through the support group, phone calls, in-person meetings, or e-mail. Most respondents indicated that their knowledge of critical services and access to services had increased, as well as their access to parent and community supports and networking. They also reported decreased stress and increased competence, resiliency, hope and healing. They attributed many of these changes to the camp experience.

Lessons Learned

The Michigan and Washington summer programs show that children, adolescents, and adults with an FASD can behave productively in a highly structured and organized age-appropriate environment with trained professionals. A supportive environment can reduce challenging behaviors and such adaptive responses can last for several days. The programs also provide evidence that effective service delivery is possible for individuals with an FASD and their caregivers.

The FASD summer program may be an effective short-term strategy, but data do not support such programs as a long-term treatment. The Michigan and Washington evaluations do not provide data beyond 3 months. Without more rigorous evaluations, it is difficult to conclude that the observations and client satisfaction reports were a valid and reliable representation of what occurred. However, when major professionals in the field collaborate to develop an intensive, short-term approach to the problems of FASD, success may be achieved.

FASD SUMMER PROGRAMS AS A PROMISING PRACTICE

The success of these two FASD summer programs and the reported success of summer camps for other special needs indicate that this strategy might have potential as a promising practice. However, the summer program is an ancillary service included in the comprehensive services offered to persons with an FASD. The summer program is not the primary intervention or a major intervention for individuals with an FASD. Research with similar populations of individuals with complex neurologic dysfunction indicates that they need comprehensive, multidisciplinary, intensive, lifelong services to maximize functioning. A 4-day program provided once or twice a year is insufficient.

The major goals of the summer programs were to teach individuals and their caregivers the skills to manage the disorder, promote positive interaction with the social and physical world, and provide respite and recreation. The two programs assessed seem to have met those goals and yielded a high level of participant satisfaction. However, they served a small number of families, so it is unclear whether such programs are appropriate for all members of this population.

Demonstrating the effectiveness of the FASD summer program through scientifically validated means requires further effort. Anecdotal evidence, observation, and participant satisfaction surveys indicate promise. In addition, many of the program components are strategies that have been found to be successful with similar populations of neurologically impaired individuals:

- Parent/caregiver training, particularly in behavior management skills
- Parent/caregiver coping and relaxation training
- Self-advocacy training
- Networking and support from those with similar problems
- Organized and structured learning environments
- Age-appropriate social and recreational activities
- Multidisciplinary staff
- Trained mentors and skilled therapists and supervisors
- Family-strengthening activities
- Structured social, communication, and problem-solving skills training and practice in real-life environments

Providing training, respite, and opportunities to practice social skills is useful as a short-term program for individuals and families affected by FASD. The summer camp program also may prove helpful in identifying components of promising and best practices for future interventions.

REFERENCES

1. Curtis, H.S. 1914. *Play and Recreation for the Open Country*. New York: Ginn and Co.
2. Mitchell, A.V., and Meier, J.F. 1982. *Camp Counseling. Leadership and Programming for the Organized Camp*. Philadelphia: Saunders College Publishing.
3. Smith, M.K. 2000. Summer camps, camp counselors and informal education. Infed.org.
4. Steele B.T., and Lirenman, D.S. 1979. Organizing a successful summer camp for children with chronic renal failure. *Canadian Medical Association Journal* 121(3):356-358.
5. Dittmann, R.W. 1982. ["Vacation dialysis"—a vacation stay for chronically ill children and adolescents with reference to psychosocial problems. Experiences with planning requirements and possibilities of realization.] *Praxis der Kinderpsychologie und Kinderpsychiatrie* 31(3):103-110.
6. Dittmann, R.W.; Hesse, G.; and Wallis, H. 1984. [Psychosocial care of children and adolescents with chronic kidney disease (in a 2-year period)—problems, tasks, services.] *Rehabilitation (Stuttg)* 23(3):97-105.
7. Klee, K.M. 1992. Benefits of a mainstreamed summer camp experience for teens with ESRD. *Advances in Peritoneal Dialysis* 8:423-425.
8. Warady, B.A. 1994. Therapeutic camping for children with end-stage renal disease. *Pediatric Nephrology* 8(3):387-390.
9. Klee, K.; Greenleaf, K.; and Watkins, S. 1997. Summer camps for children and adolescents with kidney disease. *American Nephrology Nurses' Association Journal* 24(1):57-61.
10. Myers, P. 2003. Seeing visions become realities at kidney camp. *Nephrology Nursing Journal* 30(4):472.
11. Schoberberger, C.; Schober, E.; and Frisch, H. 1981. [Summer camping for juvenile diabetics: Effects on psychological variables (author's translation).] *Padiatrie und Padologie* 16(4):427-432.
12. Yan, C.; and Miao, F.Y. 1989. Summer camps for diabetic children in Beijing of China. *Indian Journal of Pediatrics* 56 (Suppl 1):S125-127.
13. Semiz, S.; Bilgin, U.O.; Bundak, R.; et al. 2000. Summer camps for diabetic children: An experience in Antalya, Turkey. *Acta diabetologica* 37(4):197-200.
14. Mancuso, M.; and Caruso-Nicoletti, M. 2003. Summer camps and quality of life in children and adolescents with type 1 diabetes. *Acta bio-medica de L'Ateneo parmense* 74 (Suppl 1):35-37.
15. Vyhnalek, M.; and Vavrova, V. 1990. Summer and winter recondition camps for children with cystic fibrosis. *Acta Universitatis Carolinae. Medica* 36(1-4):244-246.

16. Pearson, H.A.; Johnson, S.; Simpson, B.J.; et al. 1997. A residential summer camp for children with vertically transmitted HIV/AIDS: A six-year experience at the Hole in the Wall Gang Camp. *Pediatrics* 100(4):709-713.
17. Verst, A. 1996. Burn camp: An unforgettable summer experience for children and teenagers. *Plastic Surgical Nursing* 16(4):240-241.
18. Kubin, Z.; Kubinova, E.; and Stanek, J. 1976. [The effects of summer camp for physical reeducation on children with faulty body posture (author's translation).] *Acta Chirurgiae Orthopaedicae et Traumatologiae Cechoslovaca* 43(4):335-339.
19. Candler, C. 2003. Sensory integration and therapeutic riding at summer camp: Occupational performance outcomes. *Physical & Occupational Therapy in Pediatrics* 23(3):51-64.
20. Wolpert, R.; Leuchter, S.; and Schmidt, M. 1976. Summer day camp for multihandicapped children. *Physical Therapy* 56(3):299-304.
21. Klasser, H. 1979. [Report on a holiday camp with children with behavior disorders.] *Praxis der Kinderpsychologie und Kinderpsychiatrie* 28(4):161-164.
22. Warady, B.A.; Carr, B.; Hellerstein, S.; et al. 1992. Residential summer camp for children with end-stage renal disease. *Child Nephrology and Urology* 12(4):212-215.
23. Briery, B.G., and Rabian, B. 1999. Psychosocial changes associated with participation in a pediatric summer camp. *Journal of Pediatric Psychology* 24(2):183-190.

Part 2: Michigan Conference

INTRODUCTION

In the spring of 2002, Barbara Wybrecht, a nurse in Michigan, requested support from the FASD Center for the first-ever summer conference for individuals with an FASD.* For some time, Ms. Wybrecht and her son with FAS had a dream to create a summer conference to help individuals with an FASD understand their disability and find better ways to live with it. The conference would be held in a camp setting to meet the needs of individuals with short attention spans, impulse control problems, memory problems, and a need for physical activity throughout the day. The conference site was selected specifically for individuals with an FASD to provide a more informal setting with numerous opportunities for physical activity.

After learning Ms. Wybrecht’s conceptual framework for the conference, the FASD Center joined others in supporting this unique conference. In addition, the FASD Center decided to convene one of its seven 2002 town hall meetings at the conference site in Newaygo, Michigan.

PURPOSE

The conference was called “Living and Learning With Fetal Alcohol Syndrome.” The primary goals of the conference were to provide an opportunity for individuals with an FASD and their families to:

- Increase their understanding of the brain damage caused by prenatal alcohol exposure
- Decrease their sense of isolation
- Improve their self-advocacy skills
- Decrease their risk of developing secondary disabilities

SUPPORTING ORGANIZATIONS

Initial grant funding for the conference came from the Arc of Michigan to support a learning opportunity for individuals with an FASD in an effort to prevent secondary disabilities. The table lists other contributors, supporters, and sponsors of the conference.

Organization	Donation or Grant
Speckhard-Knight Charitable Foundation	Deposit to secure the camp facilities
Parent support groups in Michigan	Planning committee members and speakers, publicity, town hall recruitment
Prevention Network	Grant for Michigan attendees’ expenses, telephone and Internet capabilities, supplies, and conference coordination
Kellogg Foundation	Funds for airfare, participant expenses, conference coordination, trainer honoraria, t-shirts, and CDs
U.S. Centers for Disease Control and Prevention	Funds for airfare, supplies, postage, conference coordination, and accounting expenses

* At the time of the conference, “fetal alcohol syndrome,” or FAS, was the preferred term. It has since been changed to “fetal alcohol spectrum disorders” to reflect changes in the field. As appropriate, “fetal alcohol syndrome” or FAS is used in this report to reflect the terminology used at the time.

FASD Summer Programs

Organization	Donation or Grant
Developmental Disabilities Institute, Wayne State University	Self-advocacy workbooks
Rural Alaska Community Action Program	Prevention posters
Gogebic Ontonagon Human Services Coordinating Board	Placemats
Kinko's	Technical assistance and discounted services
National Advisory Group for Justice and Back to Life	Development of The Right Rules workshop on dealing with law enforcement
Ollie Webb Center, Omaha	Permission to reproduce and distribute "If You Get Arrested"
Office of Juvenile Justice and Delinquency Prevention	Color copying of The Right Rules handouts
Association for Community Advocacy	Supported Employment workshop handouts
Michigan Resource Center	FAS prevention pamphlets, video catalogs, and prevention calendars

CONFERENCE OPERATIONS

The operation of the conference presented many challenges:

- More than half of the conference planning committee were individuals with an FASD. It took a great deal of patience and creativity to help them develop a conference that reflected their interests and needs while staying focused on tasks and following through on their assignments.
- Keeping all conference participants safe was a major planning focus. A support person accompanied each individual attendee. In most cases, these were parents. In a few cases, professionals worked closely with the attendees throughout the 2-1/2 days of the conference.
- It was essential for conference speakers to tailor their presentations to the needs of the audience (e.g., simple words and concrete illustrations related to the attendees' daily experiences; short presentations to fit the attendees' attention span).

PARTICIPANTS

Conference attendees and support persons came from 14 States and Ontario, Canada, as shown in the table. Support persons included 4 birth mothers, 8 professionals, 27 adoptive parents, and an aunt. Ages of individuals with an FASD ranged from 15 to 37 years.

State	Number of Attendees	State	Number of Attendees
Alaska	7	Missouri	4
Arizona	2	Montana	2
California	1	Ohio	6
Colorado	2	Ontario, Canada	2
Florida	2	Oregon	2
Georgia	2	Texas	2
Michigan	35	Washington	3
Minnesota	5	Total	77

CONFERENCE PROGRAM

General sessions are shown in the table below. Appendix A shows the conference schedule.

Title	Presenter
What Is Different About My Brain?	Edward P. Riley, PhD
What Communities and States Could Do To Help You and Your Family	Ann P. Streissguth, PhD
What Is the Federal Government Doing to Help Me?	Faye J. Calhoun, DPA
Supported Employment	Marsha Katz
WE Can Prevent FAS	Karla Damus, MSPH, PhD, RN, and Kathy Walz

Several presenters distributed handouts and Dr. Streissguth wrote a [letter to participants](#) with an FASD sharing ways to cope with their disabilities. In addition to the general sessions, individuals with an FASD and a professional or support person presented several smaller workshops, as shown in the table below.

Workshop	Facilitator
Sharing My Good Ideas About Living With FAS	Dr. Jacquelyn Bertrand
What To Do If You Are Stopped by the Police	Dr. Karen Stern
Job Success—What Helps and What Hurts?	Marsha Katz
Advocating for Myself	Marsha Katz
What To Do With the Mad That You Feel	Libby Robold (presenter)

RECREATIONAL ACTIVITIES

Recreational activities included swimming, boating, horseback riding, wall climbing, line dancing, drumming, and campfires. The site of the conference was selected specifically for this special needs population to provide a more informal setting with numerous opportunities for physical activity.

Small groups of five or six people selected, practiced, and presented [skits](#) with the theme of preventing FASD. Evaluations indicate that this was an excellent tool to assist the attendees in getting to know one another as well as conveying these important prevention messages:

- Alcohol and Pregnancy Don't Mix.
- When Pregnant, The Best Drink is NO Drink at All—Avoid Beer, Wine, and Liquor.
- I'm Getting High on Life, Not Drugs.

Through the skits, attendees practiced refusal skills several times during rehearsals and the performance Saturday night.

EDUCATIONAL ITEMS

The conference planning committee developed a t-shirt with a prevention message. The committee clearly objected to the words “Fetal Alcohol Syndrome.” However, they wanted to use the letters FAS to create a positive message. One of their concerns was how to be safe. Therefore, they created the motto “Forever Always Safe.”

Further discussion led to the suggestion of “Forever Avoid Substances.” The committee thought that avoiding substances would increase their ability to be safe. The back of the t-shirt contained the message “When You Are Pregnant, The Best Drink Is No Drink at All.” Each conference attendee and support person received a shirt.

In addition, each individual with an FASD received a sensory integration waist pack. The pack contained fidget objects and a cool gelatinous material that could be manipulated in the person’s hands. This increased individual attention span by approximately 10 minutes, which helped during plenary sessions.

Additional sensory aids were raffled off at each meal. Each person received an aid that met his or her special need. Examples were seamless socks, headphones to block out noise, special cushions providing slight motion, and talking watches for those unable to tell time.

The resource list at the end of this chapter provides citations for informational and educational articles that were distributed.

TOWN HALL MEETING

As part of the conference, the FASD Center sponsored one of its 2002 town hall meetings. The testimony from the town hall meetings will be compiled into a report for Congress. The meeting allowed participants to share their experiences, needs, frustrations, and successes in living with individuals with an FASD. They also learned from a panel of experts in the field and representatives from relevant State departments and national agencies. These included:

- Community health
- Special education
- Juvenile justice
- Family Independence Agency/Adoption Subsidy
- U.S. Centers for Disease Control and Prevention
- SAMHSA FASD Center for Excellence

EVALUATION RESULTS

To determine the usefulness of the conference, three evaluation questionnaires were used. Questions for each group follow:

- An onsite questionnaire for individuals with an FASD
 - Tell me two things you should do to make sure you do not have a baby with FAS.
 - Tell me one thing you learned about the brain and FAS.
 - Tell me two things you can do to advocate for yourself.
 - Tell me two things you should do if stopped by the police.
 - Tell me one thing you can do when you feel angry.
 - Tell me two cool things you did at this conference.

- An onsite questionnaire for support persons
 - If this conference were to be replicated in another State, list two things that should definitely stay the same.
 - List two changes you would suggest.
 - What two things can you do to help the person you are supporting remember and/or use what he/she is learning?
 - What two parts of this conference were helpful to you as a support person?
- A followup questionnaire with the support persons
 - What have you done or will you do to reteach the learnings from the conference? Please describe.
 - Has the person you supported at the conference participated in any FAS prevention activities or presentations? Please describe.
 - How did the conference affect, change, or impact the person whom you supported? Please describe.
 - If another conference were held for individuals affected by FAS or ARND, what new topics would you suggest?
 - What problems did you encounter related to the conference? How could they best be resolved?
 - What other observations/suggestions can you offer to improve a future conference? Please be as specific as possible.
 - What happy outcomes or special thoughts do you have about the contributions of this conference to the person you supported and also to you?
 - Anything else? Please be as specific as possible.

Almost universally, conference attendees and their support persons were delighted with the conference and its outcomes. Evaluations, personal notes, and anecdotal comments all reflect enthusiasm and appreciation for the event (see Appendix B for evaluation responses). Examples appear in the table.

Comment	Individual
"I don't want to go home because everyone here understands me."	Conference attendee
"I can't tell you how much I grew that weekend. Accepting and understanding what's in store for our daughter and us as a family was the greatest gift we received."	Support person
"Now I know someone like me."	Conference attendee
"For the first time we are having family discussions about FAS. This is phenomenal."	Support person
"I realized on the flight home that for the first time ever I was able to truly relax with [my daughter] around other people. I realized I was always anxious among others knowing I would be having to explain some of [her] inappropriate actions. This is because she looks normal and so is expected by others to behave that way. But at the camp I was so relaxed knowing others there understood without explanation."	Support person in a communication not included in the Conference Evaluation Summary

The findings from these questionnaires present the perspectives of the individual attendees and their support persons. In general, participants learned a great deal about FASD and related issues, such as anger management. They also appreciated the opportunity to network with persons in similar situations. Several plan to use what they learned in the future. Although some issues were raised regarding logistics, most people thought the structure of the camp was appropriate and should be retained.

Summary of Onsite Responses From Individuals With an FASD

- Nearly two-thirds (63 percent) associated FAS with alcohol consumption.
- Almost all (90 percent) associated FAS with brain damage or a diminished quality of life.
- Nearly 40 percent (37 percent) viewed accepting personal responsibility for their action as key to advocating for oneself.
- One-fourth viewed either community education or seeking treatment services as the primary way of advocating for themselves.
- Only 17 percent thought that they should mention their FAS when stopped by the police.
- Almost all (80 percent) favored self-control and redirecting their energies when they felt angry. Only 20 percent favored communicating feelings of anger.
- Half enjoyed outdoor activities more than indoor activities or friendships.

Summary of Onsite Responses From Support Persons

- If the conference were to be replicated, nearly two-thirds (61 percent) of the respondents would like to see the structure of the camp and the training sessions remain the same. Specific examples are one-on-one support, sessions by professionals such as Ed Riley, and the chemical dependency training.
- If the conference were to be replicated, support persons would favor changes in logistics and scheduling, such as length of time at camp.
- Reminders were seen as the primary strategy for helping camp attendees remember and use what they learned at camp.
- Support persons found the opportunity for adult interaction the most helpful aspect of the conference.
- General comments were all positive and reflected the participants' gratitude for what they considered to be an enriching and informative growth experience.

Summary of Followup Responses From Support Persons

- Community education was viewed as the primary way to reteach the material learned at the conference.
- Sixty percent of the camp participants had participated in FAS prevention activities or presentations after the conference.
- The main impact of the camp on attendees was that many of them realized they were not alone. Many also experienced an increase in self-confidence.
- Forty percent of respondents would like to see coping strategies included in the agenda if another camp is planned.
- Nearly half (45 percent) of the respondents experienced problems with logistics.
- Sixty percent of the respondents would like to see improvements in the planned activities for children. Examples of suggested improvements were more emphasis on self-esteem, new games, and availability of an FAS-trained counselor/therapist.
- Half of the respondents reported making new friends and connections. They viewed this as a "happy outcome."

- Support persons also made other comments that were largely positive. They emphasized the importance of being able to talk with experts, thanked the organizers of the camp, expressed interest in future camps, and expressed happiness and gratitude for the opportunity to develop relationships with others at camp.

LESSONS LEARNED

A concern in replication is determining how to engage in the planning process. The planning committee hopes that what they learned and developed can be used to help others plan and carry out a similar conference. Individuals interested in replication also need to consider the following:

- Attention to detail and long-term planning produced the desired results. Because of the time invested in speaking with each support person and some attendees on the phone, providing a detailed letter of preparation for the experience, and taking extra precautions for safety, the weekend ran smoothly. Participants were pleased with the conference, were safe and respectful of each other, and gained new insights and knowledge about FASD and the implications across their lifespan.
- This project was extremely time intensive. The amount of labor needed to operate a successful camp program is a major planning issue.
- It is important to present workshops at the cognitive level of the attendees. Recreational activities also need to be appropriate and carefully supervised. This helps to avoid injuries.
- Structured activities, positive support, and sensory integration items appeared to help. More than 50 percent of the attendees had previously been in detention, jail, or prison, but nothing was reported stolen; no fights, rages, or hostilities occurred; and no one refused to participate.
- A small but important additional budget line item to be included in the future is postage to return items left behind. Approximately 10 lost items were returned.
- Physical disabilities need to be accommodated fully. Two attendees needed crutches. Arrangements were made to transport them by car to the campfire site. However, they had to walk a short distance over uneven ground. The second night, the campfire was held in the lodge with a fireplace. At some sites, it may be necessary to make a golf cart available for transporting individuals to outdoor activities.
- Support persons who were not parents of individuals with an FASD, but professionals, did not have the in-depth understanding of the continuing needs of the attendees. In a totally new environment, among strangers and lacking social skills, the attendees needed to be closely supervised. They also need a “coach” or “consultant” to help with information processing and decisionmaking. It is important to work closely with the professional support persons to prepare them for the conference experience and their related responsibilities.

RESOURCES

- Connor, P.D. 2001. Using active imaging to unlock the secrets of FASD. *Iceberg* 11(4):4-5.
- Gelo, J. 2001. New book offers insights. *Iceberg* 11(4):6-7.
- Rathbun, A. No date. Mental health: FAS & stress—Parenting porcupines. Information available from Children’s Center, Vancouver, WA, 360-699-2244, or antoniar@thechildrenscenter.org.
- Riley, E., and Mattson, S. 2001. Using brain imaging to track FAS. *Iceberg* 11(4):1-2.
- Streissguth, A. 2000. Structure and understanding are keys for employing people with FAS. *Iceberg* 10(2):3, 6-7.
- Ten Eyck, M. 2001. 24/7 vs. letting go. *Iceberg* 11(4):3, 5.
- Wybrecht, B.M. No date. Parents: The most important protective factor.

Part 3: Washington Camp

INTRODUCTION

The first Washington State FASD Family Camp for children with an FASD, their siblings, and parents was conducted August 28-31, 2003. The camp was a huge success and represented a unique collaboration among government, university, and nonprofit community agencies. A second camp was held in August 2004 and was also very successful.

PURPOSE

The primary goal of this 4-day program was to provide children with an FASD and their families with an enjoyable and productive camp experience. The program included parent training, networking, stress-reducing efforts, family-strengthening activities, and age-appropriate social activities for children.

The camp was designed to create a safe, comfortable, physically and emotionally satisfying environment. Parents would have both respite and quality time with their children, meet other parents raising children with an FASD, and make long-term contacts.

The camp had desired outcomes for parents and children. Parents would learn new ways to advocate for their children, restructure their children's environments to minimize the effects of sensory integration deficits, and manage their children's difficult behaviors. Children would exercise their cognitive, social, fine motor, and gross motor skills in a noncompetitive and supportive atmosphere. They would be encouraged to socialize with age mates with and without similar disabilities.

CAMP PARTNERS

Four agencies coordinated the camp's support, implementation, and management:

- FASD Center for Excellence (funding, planning, and staffing)
- University of Washington, Seattle, Diagnostic and Prevention Network (DPN) (camp management and recruitment)
- Stone Soup Group (parent and counselor training in FASD)
- Volunteers of America (counselors and facilities)

PARTICIPANTS

Of 70 families invited to attend the camp, 10 families (14 percent) completed applications and attended. One father and his two newly adopted children left the first night for personal reasons. Nine families (two birth families and seven foster/adoptive families) completed the full camp experience. Sixteen adults (12 women, including 3 grandmothers, and 4 fathers) participated with their children. There were three single-parent families and six multiple-parent families. Thirty-three children attended, ranging in age from 11 days to 19 years.

Families attending the camp included 22 children diagnosed with a fetal alcohol spectrum disorder. All had been clients at the University of Washington DPN and had received a 4-digit diagnostic code in the FASD spectrum. The children's levels of functioning ranged from nonambulatory, severe mental retardation to normal intelligence, with most functioning in the moderate to mild range of disability. Several children required feeding tubes, and two were profoundly deaf.

Nine siblings without FASD also participated. They were integrated into the children's groups so that no differentiation could be observed between children with an FASD and children without an FASD.

CAMP PROGRAM

The camp structure was based on the *FASD Camp Manual* developed by the Stone Soup Group Center for Parent Navigation in cooperation with Volunteers of America, Alaska. Alaskans have used the document for the past few years to conduct their "FAScinating Families" camps for families affected by FASD. The manual suggests ways to conduct a successful camp and details the issues to consider:

- Planning
- Finances
- Camper selection
- Staffing
- Safety
- Suggested camp rules
- Crafts/activities/workshops
- Required forms such as medical releases and child profiles

Staffing

The camp staff consisted of personnel from each partner agency. A parent advocate from the University of Washington DPN team supervised the camp. An occupational therapist assisted and also helped with activity planning, coordination, and sensory integration parent training. A psychologist, epidemiologist, and pediatrician provided support as needed (for example, the pediatrician was both a clown at a family night activity and a masseur for the parents). A psychology research assistant also participated.

A parent and a teacher, representing Stone Soup Group, conducted parent training workshops on advocacy and Positive Behavioral Support (PBS). The Volunteers of America, Northwest Washington, provided counselors. Two staff from the FASD Center, a psychologist and a public health specialist, served as participant observers.

Counselor Training

The Volunteers of America counselors underwent a rigorous selection process and a weeklong training program on serving youth with developmental disabilities. In addition, counselors received training through use of the *FASD Camp Manual* and the booklet *Your Victory: A Happy Child*, by Ro DeBree, written for the FAScinating Families Camps in Alaska. This booklet describes:

- Functional deficits of children with an FASD
- Difficult behaviors and how to prevent them
- Activity accommodations required
- The need for structure and limited free time
- Ways to teach skills to children with neurologic dysfunction
- Ways to involve parents in caregiving

The University of Washington DPN and Stone Soup provided guidance to the counselors before and during the camp about management issues and activity planning. A 45-minute debriefing session was conducted with the counselors and other staff each night to discuss successes and difficulties and any modifications needed for the remaining days of camp.

Parent Training

Five parent training workshops were conducted during the 4-day camp:

- One session on advocacy
- One session on sensory integration and environmental modification
- Three sessions on PBS

The 2-hour advocacy workshop discussed situations where advocacy might be necessary, such as in schools, social services, primary care, and recreational programs. Attendees also considered the most effective advocacy methods for a given situation. Participants learned a step-by-step approach to assisting staff of various systems to understand the child's needs and ensure that those needs are met.

The 90-minute sensory integration and environmental modification workshop focused on the disorganized nervous system and related sensory integration deficits experienced by many children with an FASD. Presenters shared data indicating that 80 percent of a sample of children with an FASD had definite differences in sensory integration compared to children without FASD. Medication, occupational and behavioral therapy, and classroom accommodations were proposed to address these issues.

Participants were taught that behavior regulation issues, feeding difficulties, and noncompliance might partly result from sensory integration dysfunction. Intervention for these problems may involve modifying the child's environment, such as minimizing multiple, intense forms of stimulation. Such modifications may help children with an FASD be more successful in their daily lives.

PBS training was the primary focus of the parent training. Approximately 5-1/2 hours of PBS training were provided to participants in three workshop sessions. More parents attended the PBS training than the other two workshops. PBS is an applied science that has two major goals: expand the individual's behavior repertoire and redesign the individual's environment in a way that minimizes problem behaviors.

The initial PBS session emphasized that parents need to view their children's challenging behaviors differently from the way they had been. In the second session, participants met in small groups to learn the PBS process, selected a focus child, identified the child's strengths, and defined a target behavior. In the last session, the main concepts of PBS were introduced, such as functional behavior assessment, replacement behaviors, consequences, and goodness of fit. During this session, participants were to create a sample functional behavior assessment and PBS plan. However, plans could not be developed due to time constraints.

FACILITIES

The camp was held at the Volunteers of America Camp Volasuca site. The site is designed to provide children with special needs with traditional recreational experiences while incorporating educational and therapeutic skill building. The camp is located on 110 acres of the Sultan Basin. Facilities include woodland trails, a heated swimming pool with adjacent wading pond and bathhouse, a large A-frame

structure where meals are served, indoor recreation and lounge areas, a nurse's station, a craft cabin, eight platform tents, and two enclosed buildings. The campgrounds also include playground equipment, large playing fields for baseball and soccer, basketball and volleyball courts, and swing set areas. A trampoline, sandbox, 18-hole miniature golf course, activities stage, and fire circle are available.

EVALUATION RESULTS

This evaluation addresses:

- Fidelity of the camp structure and procedures with the planned agenda
- Participant satisfaction and the degree to which camp goals and outcomes were met as perceived by the parents and counselors
- Observations of the children and families

A 3-month followup phone interview provided additional information about the PBS training and its long-term implications.

Camp Description

The camp schedule was divided into morning, afternoon, and evening activities. Camp rules for children and parents were presented at the first evening meal and were strictly enforced during the entire camp experience. Camp events were implemented as closely as possible to descriptions written during the planning stage. Events included:

- 1-hour communal meals, where families ate together
- 30-minute family activities such as a nature walk
- Five parent training workshops
- 90-minute parent-only activities such as networking, blanket making, scrapbooking (using camp photographs taken with disposable cameras), and massage
- Children's activities in small age-appropriate groupings, including swimming, crafts, ball play, trampoline, miniature golfing, baking, and science activities
- Full camp activities, including campfire programs with songs, skits, clowns, magicians, carnivals, and movie-slumber parties

At bedtime, each child and his or her family shared a tent set up with bunk beds and clothes closets. Counselors read stories to children in their tents after the evening activity. A communal lavatory was available near the pool area. There were eight counselors, with an attempt to obtain no more than a 1:3 staff-child ratio for any age group. Counselors staffed the small group activities, with the same counselors assigned to one group of children for the duration of the camp. There was flexibility to move children among groups if one group appeared to be more appropriate than another.

Counselors also assisted during meals and were available during family time, free time, and bedtime to assist with child care. All camp activities were implemented as planned, except for the family scavenger hunt and the campfire. The campfire was canceled due to a drought in the area. During the 4-day camp, the parent workshop trainers were available to parents for individual consultation.

Participant Satisfaction Scales

Quantitative Data

The four primary partners developed the participant satisfaction scales. The scales were designed to assess whether the primary goals of the camp were met and whether any changes were recommended that might improve similar camps in the future. Several scale items were based on 3- or 5-point Likert-type scales, in which degree of satisfaction with a specified camp component was rated.

Some scale items required a yes/no or true/false answer. Others were fill-in-the-blank. Some questions were open-ended, allowing participants to share their opinions. The scales were constructed to have face validity for the participants and to provide criterion-referenced information about the camp goals and overall camp quality. Parents were asked to rate the degree to which six areas of need were met for their children. The table shows mean participant satisfaction in these areas. Scores ranged from 4.4 to 4.7 on a 5-point scale from least (1) to best (5).

Need	Average Score
Safety	4.7
Physical	4.6
Emotional	4.5
Fun	4.5
Comfort with staff	4.4
Family time	4.4

Parents were clearly satisfied that the camp met their children’s needs in these multiple domains. Safety was rated highest, so parents were extremely comfortable with the protection of their children’s safety. Lowest was family time, which indicated that parents wanted more. Since one of the major goals was to facilitate family networking, parents were asked whether they met families with whom they would like to maintain contact. Ninety percent of parents reported that they had.

The next set of questions related to the three parent workshops: advocacy, sensory integration, and PBS. Most parents (64 percent) were satisfied with the amount of time spent in the workshops. About one-fourth (27 percent) wanted more training time and one person wanted less. Average ratings on value and effectiveness were all close to 5 out of 5, as shown in the table.

Workshop	Responses	Average Score	
		Value	Effectiveness
Positive Behavioral Support	10	5.0	4.9
Sensory Integration	9	4.9	5.0
Advocacy	8	4.5	4.8

Although there was insufficient time during the workshop to create PBS plans, parents were highly satisfied with the results. A parent and an occupational therapist led the sensory integration and environmental modification workshop. Parents found it helped provide clues for understanding their children better and offered solutions. Advocacy, although of interest to parents, focused on service delivery systems. Thus, it may have been of less significance to caregivers.

The next two questions asked parents to rate their satisfaction with the length of time spent in children's and family activities. All parents were satisfied with the amount of time their children spent in their group activities. Most (73 percent) were satisfied with the length of time spent in family activities. The rest wanted more time. When parents were asked about their satisfaction with the camp length, 72 percent reported that it was just right.

No parents reported any adverse events at camp, and all said that they were willing to participate in future camps if invited. In addition, 90 percent stated that they could attend a weekend camp during the school year. Nearly all reported being willing to pay for the camp, but only six offered dollar amounts. The mean amount offered was \$163. One was willing to pay \$75, three said \$100, and two said \$300. The approximate cost per family, suggested in the Stone Soup Group manual, is \$180 for a family of 3.

The counselors received a similar questionnaire. Sixty percent thought that the camp length was just right, and 40 percent thought that it was too short. In addition, 100 percent of parents were satisfied with the structure, supervision, and safety at the camp, while 83 percent of counselors reported satisfaction in this area. All parents and counselors said that the camp was well organized and that they would recommend it to other parents.

Since most of the workshops focused on PBS, workshop participants were asked to complete a midtraining questionnaire about their knowledge and experience with PBS. Nearly two-thirds (64 percent) of participants had never heard of PBS. Only one participant had been trained in the procedures and considered the prior PBS training a valuable experience. Ten people correctly answered two out of three true/false items, and one individual correctly answered all three items.

The midtraining questions were repeated in a 3-month followup phone call to parents, which included additional questions about whether the procedures taught in the workshop had been implemented. The last question on the onsite evaluation regarding PBS asked about the participants' willingness to engage in a telephone followup. Ninety-one percent of parents agreed to participate.

Qualitative Data

Parents and counselors were asked open-ended questions regarding the most valuable camp components and areas that might be modified. For most parents, the most valuable part of the camp experience was meeting other parents of children with similar issues. Parents also valued the activities and instruction the camp provided for their children. In addition, parents wrote that they enjoyed the workshops, talks with the training leaders, and the massage and "pampering." The counselors' most valuable camp components were learning about FASD, meeting the families, and acquiring skills to manage the children's behavior.

Parents suggested the following changes:

- More parent "pampering"
- More free time, family time, and "downtime for younger children"
- More active sports in lieu of crafts
- More pool availability
- Better matching of siblings to activities
- No bedtime stories by counselors, which were disruptive to the children's settling down in their tents

Counselors suggested the following changes:

- More detailed written profiles concerning the children
- More “quiet time” for younger children
- More free time for older children
- More activities for counselors and families together so that counselors could get to know what “works” for each child
- Less family free time

Both parents and counselors were concerned about the blend of free time, family time, and active and restful activities for the varying age groups of children attending the camp. Some mismatch appeared to be observed by all. A few other suggestions were: “Put all the kids in one or two tents and the parents in another” (from a parent) and “Counselors were tired at night—the nightly (debriefing) meetings were too long” (from a counselor). The table shows some of the comments by parents and counselors.

Comment	Individual
“Well planned and staffed.”	Parent
“Loved activities for kids, training activities for parents, blanket making, networking, massage, cameras, scrapbooks (fun and relaxing).”	Parent
“Kids were kept busy; they met other kids like themselves and made friends.”	Parent
“Kids liked the carnival and clowns.”	Counselor
“Great staff-to-child ratio.”	Counselor
“Great structure.”	Counselor
“Activities made kids think and have fun at the same time.”	Counselor

These comments suggest that the camp had been planned prudently by experts in the field to meet the needs of both children with an FASD and their caregivers. The camp design incorporated the basic needs of this population of children for structure, supervision, “success” experiences, peer interaction, and supports for appropriate behavioral control. Parents and caregivers particularly appreciated the respite and relaxation, as well as seeing their children flourishing in relationships with other caregivers and age mates.

The parents’ and counselors’ exhaustion at the camp’s end exemplified the immense amount of time and energy required to raise children with an FASD. These feelings were expressed in both anecdotal comments and written responses to the questionnaire. Although this camp incorporated state-of-the-art knowledge about addressing FASD, much remains to be done to relieve the tremendous burden involved in assisting children with an FASD to live the most “normal” lives possible.

Observations

A participant-observer at the camp gained unique insights into the behavior of the children and their caregivers. Behavior differences from what would be observed in typical children of similar age included:

- More parallel than cooperative play in preschoolers
- More clinging to parents, less peer interaction, more child-adult interaction in all age groups, and continuous attention seeking from adults

- Depressed expressive language, except when modeled or cued, or out-of-context verbalizations
- Increased hyperactivity and mild self-stimulation
- Poor frustration tolerance
- Sensory integration deficits

In addition, the participant-observer noted challenging behaviors that several mothers described, such as the following:

- Asked to clean her room, the child refuses to comply, rolls her eyes, follows her mother around the room, throws things at mother and down the stairs, makes noises, rings the doorbell, goes upstairs and “tears her room apart,” climbs out the second story window or “sneaks down the stairs,” and runs off. Then she calls the police to report herself.
- “For no apparent reason,” the child hits, bites, kicks, tries to choke, and screams aggressive epithets.
- Told to “come here,” the child smiles and runs in the opposite direction; she turns around to see if mother is following.
- Told that she can’t do something, she makes a face, starts to scream, whines, kicks, grabs onto mother, and continues to demand what she is refused.

None of these acts were observed during the 4-day camp activities or they were not obvious to the casual observer. Severe problem behaviors seemed to be almost nonexistent during any of the highly structured activities, including meals, small group play, and family-strengthening exercises. Many parents reported that their children were receiving psychotropic medication, which may have contributed to the positive behavior observed during the highly structured camp activities.

Examples of procedures and activities that produced positive responses in children were:

- Imitation activities, e.g., where counselors led skits or songs
- Physical redirection by counselors, without comment or reprimand, for mild disobedience such as getting out of seat
- Fine- and gross-motor activities with prompting to avoid frustration
- Creative activities with adult cuing and support
- A variety of desired tasks, particularly when they could be “helpful”
- Reinforcers (edible, tangible, social, token, and activity)

Parental responses to children’s misbehavior included embarrassment and frustration, demands for compliance and appropriate behavior, and nagging and insistence when children did not comply. Some parents praised their children periodically for appropriate behavior, but it was considerably lower than the recommended praise/criticism ratio. Although the parents were totally dedicated to their children, some parents found it extremely difficult to fully meet their children’s needs, particularly positive adult attention and supervision.

A final observation involved the demeanor of the parents when they first came to camp, during the camping experience, and at the end. Many of the parents appeared upset and stressed on arrival at the camp. During the camp, the parents appeared to get greater enjoyment from their children and from the other adults and activities around them. Upon leaving the camp, some of the dejection appeared to return.

Camp Followup

A 3-month followup phone interview was conducted with eight of the 11 family/caregiver participants who had attended the PBS training. The percentage of correct answers on the three PBS knowledge items increased from 70 to 79. All eight said yes to the query, “Do you have a child/children with challenging behavior (i.e., behavior that puts him/her or others in danger, is disruptive to the family, or interferes with learning)?”

Seven of the parents reported that PBS concepts helped them understand their children’s needs. Six reported that they had applied information learned in the workshop to help their children in the 3 months after the camp program. These data indicate that these parents viewed PBS as a helpful method for managing behavior. All participants queried were interested in learning more about PBS procedures.

Five parents had shared PBS ideas with other important people in their children’s lives (father/mother, teacher, therapist). The parents who did not may not have a partner to share such information with or responsive alternative caregivers (such as teachers and therapists) who would be interested in these new ideas. This raises some concern about the PBS process, which requires a team approach to implement the PBS plan with the child across settings.

Nine parents and caregivers who attended the 2003 camp attended a similar camp in 2004, which was not sponsored by the FASD Center. However, they completed a followup form providing feedback on the 2003 camp and whether it had improved their situations. All indicated that they remain in contact with individuals they met at the 2003 camp, some as often as daily. Improvements included more confidence; access to resources such as support groups, a teen group, and adoption support; greater ability to advocate; and more knowledge about individualized education plans (IEPs).

Eight of the nine parents and caregivers attributed the improvements to their camp experience. Specifically, they noted greater understanding of PBS and the IEP process; increased connections to professionals, services, and new friends; and teamwork, understanding, and compassion. The general feeling was that they do not feel so alone and know there are other families they can rely on. The support group, listserv, and teen group formed among camp participants have been particularly helpful.

The 2004 camp received positive evaluations as well. Including parents and caregivers who attended in 2003, 21 evaluations were received. In addition, six counselors completed evaluations. Parents, caregivers, and counselors all gave the camp high marks. The table shows the average scores of parents and caregivers on a scale of 5 for various needs addressed by the camp.

Need	Average Score
Fun	4.7
Family time	4.6
Emotional	4.4
Comfort with staff	4.4
Physical	4.3
Safety	4.3

Parents/caregivers thought the workshops were extremely valuable, as were the parent networking and respite opportunities. Activities for children and families received high marks. One parent noted, “The kids were happy, engaged, and well cared for.” Negative comments primarily related to logistical matters, such as noise at meals and dirty bathrooms.

LESSONS LEARNED

The successful accomplishments of the Washington State FASD family camp were partly due to the excellent group of partners sponsoring the camp. They had extensive experience in general human services and FASD in particular. The knowledge and experience brought to this endeavor by this unique partnership of government, academic, and community agencies serves as an example for human service efforts that support the Government’s science-to-service objective.

Management of campers’ behavior was based on a person-centered, strengths-based vision. The child’s environment was modified to promote positive behavior in natural settings. This approach appeared to be successful with both the parents and children participating in the camp, reducing stress levels of caregivers and problem behaviors in children.

Parents and caregivers responded well to stress reduction activities. Research in behavioral treatment of anxiety and tension has indicated that persons need to be taught self-relaxation skills to make long-term gains in stress reduction. Thus, in addition to or in lieu of massage, parents and caregivers might be trained in progressive relaxation techniques that they can use at home. Relaxation tapes to be sent home with parents and caregivers is an excellent way to remind parents to care for themselves as well as their children.

Because a small number of families attended, results may not be generalizable to the entire population of families affected by FASD. For example, it is extremely difficult for families of children with special needs, particularly large families, to leave their homes for several days. Such constraints may limit the viability of the camp concept as a therapeutic intervention for this population.

The success of this camp in providing effective services for families should not be overlooked. Combining parent training and stress reduction strategies with developmentally appropriate skill-building activities for children to address their sensorimotor, physical, social, communication, and adaptive behavior issues may remain the treatment of choice. However, these services may require delivery in a less time-intensive venue than camp. Weekly sessions over an extended period of time may be more feasible. The FASD field greatly needs effective interventions, and these components may well be present in the strategies delivered through this camp program.

The question arises whether organizations without an established partnership such as that involved in the Washington camp could implement a high-quality program. Stone Soup Group and Volunteers of America have previously collaborated in Alaska on the FAScinating Families Camps. Limited process evaluation data indicate that the program was effective. However, outcome evaluations will be needed to determine the viability of this program model. The Washington Camp evaluations, although positive, were not structured in a way that allows any conclusions to be drawn regarding the effectiveness of the camp in effecting meaningful change.

Appendix A

**Living and Learning
With Fetal Alcohol Syndrome
Conference Schedule**

Appendix A
**Living and Learning
With Fetal Alcohol Syndrome
Conference Schedule**

Thursday

6:00 to 9:00 p.m.		Arrive at Camp
6:00 to 8:30		Dinner and Tour of Camp (Rolling Dinner Hour due to varying arrival times)
8:00	Idema Theater	Welcome from Eric Richards, The Arc Michigan Dr. Jacquelyn Bertrand, CDC Barbara Wybrecht, Introduction of Planning Committee
8:15	Idema Theater	Dr. Faye Calhoun, NIAAA "What Is the Federal Government Doing To Help Me?"
9:00	Idema Theater	Drumming, Patricia Hickey
10:00		Lights Out or Quiet Activities in the Dining Hall Board Games "Getting To Know You" "Who Wants To Be a Millionaire?"
11:00		The day is done. Get a good night's sleep. Tomorrow will be a busy day.

FASD Summer Programs

Friday

7:00 a.m.	Wake Up Bell	
8:00	Breakfast	
9:15	General Session Idema Theater	“What Is Different About My Brain?” Dr. Ed Riley
10:00	Sensory Diet Break	
10:10	General Session Idema Theater	WE Can Prevent FAS Dr. Karla Damus, Kathy Walz “Remembering What We Know” Role Play Demonstration—Conference Committee
11:00	Sensory Diet Break	
11:10	Small Groups Idema Theater	Sharing My Good Ideas About Living with FAS Dr. Jacquelyn Bertrand, Karyann Clark, Tony Kezenius, Mary Van Swol, Liz Kulp Myrhez, Shaun Notten
	Millar Lodge	Advocating for Myself, Telling Others What I Need Marsha Katz Star Child Quilt (Cancelled)
12:00 noon	Lunch	Meal Ticket—“Two Things I Like About Me”
1:00 to 4:30 p.m.	Everyone	Open Recreation Swimming Tower Climbing Woodworking Fishing Horseback Riding Nature Trail Canoeing Star Child Quilt Conversations with Dr. Calhoun, Dr. Riley, Marsha Katz, Dr. Streissguth, Dr. Bertrand, Dr. Stern, Dr. Damus
4:30	General Session Idema Theater	Supported Employment — Marsha Katz
6:00	Dinner	Meal Ticket—“Two Things I Do Well”
7:00	Trying Out Refusal Skills—Choosing and Practicing Role Plays	
8:00	Line Dancing—Idema Theater	
9:00	Campfire with John Brewer	
10:00	Lights Out, or in the Dining Hall, board games, creating a Prevention Poster, “Who Wants To Be a Millionaire?” “Getting to Know You”	
11:00	Another day comes to an end. We told you! It was busy (and tiring), wasn’t it?	

FASD Summer Programs

Saturday

7:00 a.m.	Wake Up Bell	
8:00	Breakfast	
9:00	General Session Idema Theater	“What Communities and States Could Do To Help You and Your Family” Dr. Ann Streissguth
9:45	Sensory Diet Break	
10:00	Small Groups Idema Theater	Panel—Job Success - What Helps and What Hurts Marsha Katz, Melissa Clark, Cindy Gere, John Kellerman
	Millar Lodge	What To Do When You Are Stopped by the Police Dr. Karen Stern, Rob Wybrecht
	Craft Cottage	What Do You Do With the Mad That You Feel? Libby Robold, Mary Van Swol, Ben Brewer
11:00	Video Taping - Group One – Millar Lodge	Nature Walk - Group Two
12:00 noon	Lunch	
1:00 p.m.	Video Taping - Group Two – Millar Lodge	
12:30 to 5:00	TOWN HALL MEETING	
1:00 to 5:00	Open Recreation	
5:00 to 6:00	Complete Video Taping, Practice for Skit Night	
6:00 to 7:00	Dinner	
8:00	Skits Just for Fun or with an FAS Prevention Message – Idema Theater	Support persons, professionals, important guests included
9:00	Campfire with Libby Robold	
10:10	Lights Out, or Dining Hall activities. Tomorrow, Sunday, breakfast will be available at 6:30. The bus is scheduled to leave for the airport at 7:15. Because of incoming activities, we must vacate the camp by 9:00 a.m.	

Sunday

6:30 a.m. Breakfast available. 7:15 Bus leaves for airport. Everyone out by 9:00.

Appendix B

Summary of Michigan Conference Evaluation Responses

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Summary of Michigan Conference Evaluation Responses

Note: FAS is used to refer to fetal alcohol spectrum disorders because FAS was the term used when the survey instruments were administered.

SUMMARY OF ONSITE EVALUATION RESPONSES FROM AFFECTED INDIVIDUALS

The tables summarize the responses to each question. After each table, selected comments are listed.

Question 1. Tell me two things you should do to make sure you do not have a baby with FAS.

Response Categories	Number	Percent
Conditional abstinence from alcohol (e.g., not drinking when pregnant)	8	42
Abstinence from non-alcohol-related substances and activities (e.g., drugs, sex)	6	32
Complete abstinence from alcohol	4	21
Other responses (e.g., take folic acid)	1	5
Total	19	100

Question 2. Tell me one thing you learned about the brain and FAS.

Response Categories	Number	Percent
Brain size (e.g., FAS brain smaller than normal)	5	50
Brain damage	3	30
Quality of life (e.g., difficult living with FAS)	1	10
Abstinence	1	10
Total	10	100

Question 3. Tell me two things you can do to advocate for yourself.

Response Categories	Number	Percent
Personal responsibility (e.g., say no)	6	37
Community education about FAS	4	25
Treatment services/seeking assistance	4	25
Legislative action/awareness of FAS risk	2	13
Total	16	100

Question 4. Tell me two things you should do if stopped by the police.

Response Categories	Number	Percent
Provide standard information (e.g., show ID)	8	44
Control emotional responses	7	39
Mention FAS	3	17
Total	18	100

Question 5. Tell me one thing you can do when you feel angry.

Response Categories	Number	Percent
Redirect my energy	4	40
Maintain self-control	4	40
Communicate the feeling	2	20
Total	10	100

Question 6. Tell me two cool things you did at this conference.

Response Categories	Number	Percent
Outdoor activities	10	50
Friendships	5	25
Indoor activities	5	25
Total	20	100

SUMMARY OF ONSITE EVALUATION RESPONSES OF SUPPORT PERSONS

Question 1. If this conference were to be replicated in another State, list two things that should definitely stay the same.

Response Categories	Number	Percent
Structure (e.g., one-on-one support, small groups)	11	35
Sessions (e.g., training, drumming)	8	26
Professionals in attendance	5	17
Location	3	10
Specific activities (e.g., horseback riding)	2	6
Interactions among children	2	6
Total	31	100

Question 2. List two changes you would suggest.

Response Categories	Number	Percent
Logistics	9	43
Scheduling/length of camp	6	28
Activities	3	14
Support (e.g., caregiver support)	2	10
Meals	1	5
Total	21	100

Question 3. What two things can you do to help the person you are supporting remember and/or use what he or she is learning?

Response Categories	Number	Percent
Review sessions/reminders	10	40
Communication	8	32
Support groups	5	20
Self-empowerment	2	8
Total	25	100

Question 4. What two parts of this conference were helpful to you as a support person?

Response Categories	Number	Percent
Adult interaction	12	48
Interaction with children	5	20
Interaction with experts	4	16
Opportunity to be heard	4	16
Total	25	100

Other Comments

Response Categories	Number	Percent
General thanks	4	67
Knowledge gained/networking opportunities	2	33
Total	6	100

SUMMARY OF FOLLOWUP EVALUATION RESPONSES OF SUPPORT PERSONS

Question 1. What have you done or will you do to reteach the learnings from the conference? Please describe.

Response Categories	Number	Percent
Community education	3	38
FAS training and education	2	25
Reminders	2	25
Advocacy with criminal justice system	1	12
Total	8	100

Question 2. Has the person you supported at the conference participated in any FAS prevention activities or presentations? Please describe.

Response Categories	Number	Percent
Yes (e.g., March of Dimes fundraiser, Alaska FAS Summit)	6	60
No	3	30
Don't know	1	10
Total	10	100

Question 3. How did the conference affect, change, or impact the person whom you supported? Please describe.

Response Categories	Number	Percent
Realizing he or she is not alone	4	37
Increased self-confidence	3	27
Self-advocacy	2	18
Unknown	2	18
Total	11	100

Question 4. If another conference were held for individuals affected by FAS or ARND, what new topics would you suggest?

Response Categories	Number	Percent
Coping strategies	4	40
Anger management	2	20
Social skills	2	20
FAS-related limitations	1	10
Age-related topics (e.g., jobs post-high school, making and keeping friends in middle and high school)	1	10
Total	10	100

Question 5. What problems did you encounter related to the conference? How could they best be resolved?

Response Categories	Number	Percent
Meeting logistics (e.g., length of town hall)	4	45
No conference-specific problems	3	33
Accommodations	2	22
Total	9	100

Question 6. What other observations/suggestions can you offer to improve a future conference? Please be as specific as possible.

Response Categories	Number	Percent
Planned activities for children (e.g., games where everyone wins, open forum for campers)	6	60
Planned activities for support persons	2	20
Meals and accommodations	2	20
Total	10	100

Question 7. What happy outcomes or special thoughts do you have about the contributions of this conference to the person you supported and also to you?

Response Categories	Number	Percent
New friends/connections	4	50
FAS information	3	38
No significant life changes	1	12
Total	8	100

Question 8. Anything else? Please be as specific as possible.

Response Categories	Number	Percent
Relating to other FAS children	2	25
Importance of the experts	2	25
Request for future camps	2	25
Other	2	25
Total	8	100